

Inpatient transfer to a care home for end of life care: what are the views and experiences of patients and their relatives? A systematic review and narrative synthesis of the UK literature.

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What is already known about the topic?

- Transfer to care homes for end of life care is increasingly common in the UK
- Public opinion surveys indicate few would choose a care home as their preferred place of death
- Relocation to live in a care home is a stressful life event

What this paper adds?

- There is no literature regarding patients experience of transferring from hospital to die in a care home
- There is indirect evidence to suggest that patients find the process of moving from hospice to care home stressful
- Relatives find the experience of looking for care homes when their loved one is terminally ill in a hospice, traumatic.

Implications for practice, theory or policy

Research is needed to understand patients' views about transferring to care homes for end of life care and how such decisions around transfers are made

Key words: terminal care, nursing homes, patient discharge, hospices, hospital

Abstract

Background

Transfers from hospital or hospice 'palliative care units' to care homes for end of life care are an increasingly common part of clinical practice, but are a source of anxiety and distress for patients, relatives and healthcare professionals.

Aim

To understand the experiences of patients discharged to care homes for end of life care

Design

Systematic review and narrative synthesis of the UK literature concerning inpatient transfer from a hospital or hospice palliative care unit to a care home for end of life care.

Results

The published literature is very limited: only three papers and one conference abstract were identified, all of low quality using Gough's weight of evidence assessment. No papers examined transfer from hospital: all were of transfers from hospices and were retrospective case note reviews. Many patients were reported to have been negative or ambivalent about moving and experienced feelings of anxiety or abandonment when transferred. Relatives were often either vehemently opposed or ambivalent. Though some came to accept transfer, others reported the transfer to have seriously affected their loved one's quality of life, and that the process of finding a care home had been traumatic. No studies investigated patients' views prospectively, the views of staff or the processes of decision-making.

Conclusion

The UK literature is very limited, despite such transfers being an increasingly common part of clinical practice and a source of concern to patients, relatives and staff alike. Further research is urgently needed in this area, especially studies of patients themselves, in order to understand their experiences and views.

Background

The most common place of death in England and Wales is in hospital (1), despite surveys indicating that most people would prefer to die at home (2). Whilst hospital is the least popular choice for place of death, care homes come a close second as unpopular places to die (2). National Health Service End of Life Care policy in the UK has focused upon reducing the number of hospital deaths and enabling more people to die at home (3), (4), a strategy that aligns well with the pressure upon hospital beds and the drive to reduce inappropriate admissions. The discourse around 'choice of place of death' is often presented as a choice between hospital and home (5), (6). Although death at home may be an achievable option for some, a significant proportion of people (21%) die in care homes (1), despite few people expressing a preference to do so (2). If death in an institution is necessary, in the UK, most would choose to die in a hospice (2) and the proportion of people preferring death in a hospice over home, increases with age (7) (2).

The meaning of hospice varies across healthcare systems (8). In contrast to the US, where 'hospice' refers to a programme of care, in the UK it is a term commonly used to describe a stand alone organisation run as an inpatient Palliative Care

Unit. The European Association of Palliative Care defines a Palliative Care Unit as 'a department specialised in the treatment of palliative care patients where the aim is to 'stabilise patients..... [in order to] allow discharge to another care setting'(9). Such hospice palliative care units have a limited number of beds (mean =15) (10) with an average length of stay of approximately 2 weeks (10) and provide care for those with the most complex or unstable symptoms. Care is free: funded by charitable donations, with National Health Service contributions. In the UK, discharge from a hospice means discharge to a different care setting once a crisis is stabilised –usually home, but sometimes to a care home.

By contrast, care homes are private institutions that provide an alternative form of accommodation with nursing care. In most cases the care home becomes that person's home, which may therefore involve them selling their property to fund their move. Some means tested funding is available from the local authority, or from the National Health Service Continuing Health Care budget if the person is deemed to have high nursing needs.

For the purposes of this review, inpatient hospice care in the UK is taken to broadly reflect the EAPC definition of a palliative care unit, and is distinct from a

care home in terms of focus and intensity of nursing care, specialist palliative care staff, length of stay and funding. See figure 1 for a schematic representation of the flow of admissions and discharges at the end of life in the UK.

The UK National End of Life Care Intelligence Network counts the proportion of 'deaths in usual place of residence' as a key performance indicator for end of life care and a proxy marker for quality (11). Although death in a care home is considered to be in a person's usual place of residence, those who are transferred to a care home for the last few weeks of life may neither consider it to be their home, nor their preferred place of death. Choice and autonomy are known to be reduced for the frail elderly (12), (13) (14). People transferred to care homes from hospitals or hospice palliative care units, may have little say in where they are placed and be under considerable pressure to move "to free up a bed". If transferred from hospital they are commonly deemed not to have the "specialist needs" or "short enough prognosis" to be referred to a hospice palliative care unit. Patients who have deteriorated rapidly, requiring an initial admission to hospital or hospice palliative care unit, may find the prospect of transfer to a care home unexpected, potentially stressful and therefore burdensome during the final few weeks of life.

Aim

Although the views of patients who are admitted to live in care homes have been extensively studied, the views of those admitted to die in one have not (15). The aim of this study was to undertake a systematic review of the literature concerning inpatients who are moved to care homes from hospital or hospice palliative care unit near the end of life.

Because the meaning of hospice care has such international variation in terms of levels of care provision and funding, it was decided to focus on data from the UK healthcare system. However the results have relevance for healthcare systems where palliative care units offer short stay placements for those with complex needs, as opposed to care homes which provide long term residential or nursing care.

Review questions

Concerning patients transferred from hospital or hospice palliative care unit to a care home for end of life care:

- 1) What are the views and experiences of the patients?

- 2) What is their preferred place of death?
- 3) What are the views and experiences of the relatives of these patients?
- 4) How are decisions made about these patient transfers?
- 5) What are the views of healthcare professionals about these transfer decisions?

Design

A search strategy was devised with the support of an Information Technologist (IK) to address the review questions (Table 1). Medline, Embase, CINAHL, PsycINFO, Web of Science, SCIE and ASSIA databases were all searched, yielding a total of 6,989 hits. Following exclusion of irrelevant and duplicate titles (Figure 2), 542 abstracts were read independently by the authors (TT and SB), yielding 11 potential papers. Inclusion criteria included: transfers to care home for End of Life Care, data from UK health and social care system and publication in English language. Exclusion criteria included: transfers from community settings to care homes, studies of the experience of care and / or dying in care homes that did not involve a transfer from hospice or hospital and papers with no new empirical data. Both researchers read these 11 papers, of which only 3 research papers and one

conference abstract met the criteria for inclusion in the synthesis. Hand-searching of Palliative Medicine from 1994 to 2015 identified no additional papers.

A review-specific data extraction tool was used to record data relevant to the review questions (Figure 3). Both reviewers independently used Gough's weight of evidence framework (16) to weight the included studies contribution to the review. This involved determining the coherence and integrity of the evidence in its own terms, the appropriateness and relevance of research focus for answering the review question (Table 2).

Results

All four papers related to the transfer of patients from hospice to care home: no papers addressed hospital to care home transfer for end of life care. Two studies were retrospective case note reviews from one hospice conducted in 1999/2000 (15) and 2004/5 (17): they examined demography, length of survival and the views of patients or relatives about the transfer recorded in the notes. One study interviewed relatives of all those transferred to care home from a hospice during 1991 and had subsequently died (18). The final paper, a conference abstract,

reviewed 10 discharges from a hospice to care homes, but gave no information about how that review was conducted (19).

All studies were retrospective, with no direct information from patients themselves. Both reviewers rated the weight of evidence of all four papers as low, according to Gough's criteria (Table 2).

1) What are the views and experiences of patients regarding transfer?

Three studies documented the number of patients who were considered for transfer from hospice and the number actually transferred: in all three studies only a minority were ultimately moved (Table 3). Two documented length of survival following transfer to a care home: all except 1 died within 11 weeks of transfer, a significant proportion within 3 weeks: 5/6 (87%) (17) and 6/16 (37%) (15). One reported a median survival of 67 days after care home transfer was initially discussed, with a range of 3-168 days (18): the survival of patients once they had been transferred from the hospice was not stated. Three studies described a minority of patients that did not die in the care home to which they were transferred, but died in hospice, own home or another care home (15), (17), (18).

Of the patients with whom a care home transfer was broached, 33% were negative or ambivalent (15) and 50% unhappy (17). One patient objected very strongly and was allowed to stay in the hospice (17). One study reported over half of patients to have declined to proceed to transfer, and that half who were moved had not wanted to leave the hospice, according to their relatives (18). Another study found that all patients who were transferred experienced feelings of anxiety or abandonment (19). However, 3 patients stated they were keen to leave the hospice (15).

2) What were the preferred places of death of the transferred patients?

This was not stated in any of the papers. One reported that 11 patients and carers had stated they wished care to continue at the hospice (15). Two reported patients who returned to hospice to die (18) (17).

3) What were the views and experiences of relatives of transfers?

The views of relatives are documented more clearly. In both retrospective case note reviews half of relatives were vehemently opposed (17) or negative / ambivalent (15) to the idea of transfer out of the hospice, whilst half came to accept

it (17) and a third were positive or accepting (15). Interviews with relatives post bereavement found 60% felt that the transfer to care home had seriously affected their loved one's quality of life and 30% had found the process of finding a care home 'traumatic and terrible' (18). The more the relatives were involved with the transfer process, the longer it took (19).

4) What were the views and experiences of healthcare professionals?

This was not addressed in any of the studies although hospice staff discomfort with care home transfers provided the impetus for one study (15), and another mentioned in the discussion that some staff 'struggle with the fact that a small proportion of patients remain in the hospice much longer than others' (17),

5 How are decisions concerning transfers made?

No studies addressed this question, although one indicated this to be an important aspect to investigate (17).

Discussion

This review has identified that the literature concerning inpatient transfer to care home for end of life care to be very limited. Most patients who have experienced hospice inpatient care do not wish to move again, and their relatives find the prospect of finding a care home very stressful. There is little known about patient experience before and after these transfers, despite their being an increasingly common part of clinical practice.

Although this review demonstrates a paucity of information on transfer to care homes at the end of life, there is a considerable international literature around relocation of the elderly into long term care facilities at a point when they are not regarded as actively dying. Relocation in these circumstances is reported to be stressful, involving significant losses and adjustments (20) (21) and often occurs at a time of crisis in health or the death of a spouse (22). Studies of older peoples' experiences of moving to such long term residential care have found both positive and negative attitudes to relocation, as well as passivity and resignation (20), (23), (24), (25), (12). Several months are required for adjustment and significant support is needed during this transition. 'Relocation stress' (22) is related to individual's

degree of choice and involvement in the decision to move, the ability to legitimise it and to perceive the move as reversible (26) (23). Many care home residents wish to live 'day to day', do not wish to plan for the future and do not view the care home as their final destination (12) (25).

There have been steady changes in the demography of UK nursing home residents over recent years (27). Reductions in the numbers of hospital beds and a focus on reducing 'inappropriate' hospital admissions has meant that in the UK, care homes have increasingly moved away from being an 'alternative form of housing for frail older people, towards a location of last resort for individuals with high support needs towards the end of life' (27). The average length of stay in care homes is declining, with 50% of residents dying within a year of admission (28), suggesting that care homes are taking on a significant role in end of life care. At the same time, concern has been raised about the quality of end of life care in care homes (29), with numerous initiatives to raise standards (30) (31) (32) at times hindered by high staff turnover, lack of access to General Practitioner support and lack of staff training (33) (34).

Relocation to a care home for terminal care may involve change in area, change in General Practitioner and reduction in support from specialist palliative care (35), compounded by the loss of home and lack of time available to adjust to new surroundings (36).

There may be a number of reasons why, in the UK, a care home is rarely peoples' preferred place of care and death in surveys: media reports highlighting poor care and neglect, financial concerns, leaving loved ones behind, among others. Hospice care is often preferred above a care home (2) (6) (37). However, the prospect of such institutional care becomes more appealing when individuals are faced with the reality of significant care needs towards the end of life (38) (39) (37) (12). A move to a care home for end of life care may not ultimately be distressing: the relief of being secure and 'looked after' when care needs are considerable and increasing, may outweigh any negative aspects (12). It has been suggested that for some approaching the end of life, concerns about lack of choice around where they are looked after may be of lesser importance: the identity of dying is stronger than care home resident status and takes precedence over location of care (20).

Conclusions

The research literature concerning inpatient transfers from hospital or palliative care unit to care home for end of life care is very limited, despite such transfers being an increasingly common part of clinical practice and a source of concern to patients, relatives and staff alike. Further research is urgently needed in this area, especially studies of patients themselves in order to understand their experiences and views. Better understanding is needed on the effects of such transfers, or discussions of transfers, on their quality of life and quality of care, in order that they, and their relatives, can best be supported in their final weeks of life.

References

(1) Mortality Data 2013. Office for National Statistics, London, 2014.

<http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-327590> Table 12 (accessed July 2015)

(2) Gomes B, Calanzani N, Higginson I. Local preferences and place of death in regions within England. Report, Cicely Saunders Institute, UK. 2011

(3) Department of Health. End of Life Care Strategy: promoting high quality care for all adults at the end of life p136 and p159. London: Department of Health 2008

(4) NICE Commissioning Guides: Guide for commissioners on end of life care for adults 2011

(5) Addington-Hall JM, O'Callaghan AC. A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: results from a survey using the VOICES questionnaire. *Palliat Med* 2009; 23:190-197

(6) Grande G. Palliative care in hospice and hospital: time to put the spotlight on neglected areas of research. *Palliat Med* 2009;187-189

(7) Catt S et al. Older adults' attitudes to death, palliative treatment and hospice care. *Palliat Med* 2005; 19(5):402-410

(8) Payne S et al. White paper on standards and norms for hospice and palliative care in Europe part 1. *Eur J Pall Care* 2009; 16(6):278-289

- (9) Radbruch L et al. White paper on standards and norms for hospice and palliative care in Europe part 2. *Eur J Pall Care* 2010; 17(1):22-32
- (10) National Council for Palliative Care: National survey of patient activity data for specialist palliative care services: MDS full report for the year 2012 – 2013
- (11) National End of Life Care Intelligence Network : http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death (accessed July 2015)
- (12) Mathie E et al. An uncertain future: the unchanging views of care home residents about living and dying. *Palliat Med* 2012; 26: 734-743
- (13) Wheatley VJ, Baker JI. "Please, I want to go home": ethical issues raised when considering choice of place of care in palliative care. *Postgrad Med J* 2007; 83: 643-648.
- (14) Rolls L, Seymour J, Froggatt K, Hanratty B. Older people living alone at the end of life in the UK: Research and Policy Challenges. *Palliat Med* 2010; 25(6): 650-657
- (15) Enes SP et al. Discharging patients from hospice to nursing home: a

retrospective case note review. *Int J of Pall Nurs*, 2004;10(3)124-130

(16) Gough D. Weight of Evidence: a framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education* 2007;22(2):213-228

(17) Reith M, Lucas C. Questioning the evidence for service assumptions: audit of transfers from a hospice to nursing home care. *J Soc Work* 2008; 8(3): 233-245

(18) Maccabee J. The effect of transfer from a palliative care unit to nursing homes--are patients' and relatives' needs met? *Palliat Med* 1994; 8(3): 211-214

(19) Traxler, P. Challenges in the transfer of patients from hospice to nursing home: a model for future partnership. *BMJ support palliat care* 2011; 1(2): 261

(20) Nay R. Nursing home residents' perceptions of relocation. *J Clin Nurs* 1995; 4(5): 319-325

(21) Gladman J, Albazzaz M, Barer D. A survey of survivors of acute stroke discharged from hospital to private nursing homes in Nottingham. *Health Trends* 1991;23(4):158-160

(22) Melrose S. Reducing relocation stress syndrome in long-term care facilities. *J*

Pract Nurs 2004; 54(4):15-17

(23) Nolan M et al. Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *J Adv Nurs* 1996; 24(2):265-274

(24) Reed J, Morgan D. Discharging older people from hospital to care homes: implications for nursing. *J Adv Nurs* 1999; 29(4): 819-825

(25) Lee VS, Simpson J, Froggatt K. A narrative exploration of older people's transitions into residential care. *Aging Ment Health* 2013;17(1): 48-56

(26) Chenitz WC. Entry into a nursing home as status passage: a theory to guide nursing practice. *Geriatr Nurs* 1983; 4(2): 92-97

(27) Lievesley N et al; The changing role of care homes. BUPA and Centre for Policy on Aging 2011

(28) Kinley J et al. The provision of care for residents dying in U.K. nursing care homes. *Age Ageing* 2014;43:375-379

(29) Care Quality Commission. The state of health care and adult social care in

England October 2014

(30) Hockley J et al. The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliat Med* 2010;828-838

(31) Finucane AM et al. Improving end-of-life care in nursing homes: implementation and evaluation of an intervention to sustain quality of care. *Palliat Med* 2013;27(8):772-778

(32) Badger F et al. An evaluation of the implementation of a programme to improve end-of-life care in nursing homes. *Palliat Med* 2009; 23: 502-11

(33) Seymour JE, Kumar A, Froggatt K. Do nursing homes for older people have the support they need to provide end-of-life care? A mixed methods enquiry in England. *Palliat Med* 2011;25:125-138

(34) Goddard C et al. Providing end-of-life care in care homes for older people: a qualitative study of the views of care home staff and community nurses. *J Appl Gerontol* 2013; 32(1):76-95

(35) Froggatt KA, Poole K, Houlst, L. The provision of palliative care in nursing

homes and residential care homes: a survey of clinical nurse specialist work.

Palliat Med 2002;16(6): 481-487

(36) Porock D et al. Relocation stress syndrome: the case of palliative care patients. *Palliat Med* 1997;11(6) 444-450

(37) Catt S et al. Older adults' attitudes to death, palliative treatment and hospice care. *Palliat Med* 2005;19(5):402-410

(38) Gott M et al. Older people's views about home as a place of care at the end of life. *Palliat Med* 2004;18(5):460-467

(39) Gerrard R et al. Achieving the preferred place of care for hospitalized patients at the end of life. *Palliat Med* 2011; 25 333-336